

**The Importance of Family History in Health**  
*Alan Guttmacher, M.D.*

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DR. COLLINS: Thanks for telling just about everybody about that, Reed. That's much appreciated, and I probably will need the support.

Well, it's my pleasure to introduce Alan Guttmacher, who is going to give this presentation on the importance of family history in health. Alan has a distinguished career as a physician in the area of medical genetics and pediatrics. For some time, he was the only board-certified medical geneticist in the State of Vermont, and also ran the first newborn intensive care unit in the State of Vermont.

The State of Vermont went into severe mourning when I recruited Alan to come to NIH because, as you can imagine, their census dropped rather dramatically in terms of these kinds of capabilities. But since he has been here for the last five years, he's become an absolutely essential part of what we're trying to do in the genomic arena, and he runs our Office of Policy Education and Communication, as well as a host of other issues, and he has been the point person in our discussions with the Surgeon General about a particular initiative on family history that I think he is going to tell you something about.

I would also just like to say, because it happens to be the very day when this is being announced, that Alan has been elected to the Institute of Medicine as of today. So congratulations, Alan.

(Applause.)

DR. GUTTMACHER: When Francis said he wanted to introduce me, I knew there was some way he was going to try to embarrass me. Since I recently introduced him, I was quite concerned. I thought it might be even worse than that. But thank you.

This is a very important issue. In fact, the Surgeon General had hoped to be here to be able to give this talk. He's very sorry that because of another commitment he couldn't be here. I'm very sorry that because of another commitment he couldn't be here. I hope you won't be too sorry that because of another commitment he couldn't be here to talk about a trans-departmental initiative that the Surgeon General is really spearheading, and that has to do with family history.

So first I thought I'd talk a little bit about the importance of family history and health. I realize that this will be largely preaching to the choir, but I'm going to end the sermon by letting everyone know how we can use our voices together to sing and preach to a larger choir than just the folks in this room.

If this is the age of genomics, as we much trumpet it, why should family history be important? It seems sort of old-fashioned, the kind of thing you might, heaven forbid, use a pencil and piece of paper about and not that sophisticated genomic tool, et cetera. Well, of course, we know, in the age of genomics, that most diseases are due to an interaction of multiple genes and environmental factors. So we know that, but what do we do with it?

Well, we should remind ourselves that today, almost every patient that is seen has available a free -- I would underscore "free" since that's unusual medicine -- personalized tool that captures many of those genetic and environmental interactions and can serve as a cornerstone for individualized disease prevention. That tool, of course, which has stood the test of time, the other thing to be said for it, is the family history.

Now, even though we will, of course, continue to gain important new genomics tools in the years ahead, and those are the kinds of things that this committee has been thinking about and their impact on health care, family history is going to remain relevant for many years to come, and in fact will become more useful because it has to do with such varied health concerns as you see here -- heart disease, colorectal cancer, breast cancer, ovarian cancer, osteoporosis, asthma type 2, diabetes, suicide. You can go on and on. Most of the common, significant causes of morbidity and mortality that we have, in fact, family history can contribute to our understanding of them and certainly our approach to individual patients.

Yet nonetheless, most people, many people certainly, are unaware of their relevant medical histories, and many of us health professionals under-utilize this information in advising our patients about how to maintain good health.

For instance, you can use family history information to affect the way that you do population screening for all of these different kinds of conditions, a large array of conditions to which family history is pertinent. Then beyond screening in terms of our management of various conditions, again a large slew of conditions for which we have good data to show that family health history can in fact make a difference in management.

So if this is so useful, why aren't health professionals using it more consistently and more effectively? All of us who have a clinical background would be embarrassed probably to talk about the way we individually use the family history but would certainly be embarrassed to talk about how all health care providers in general, our professions tend to do that.

I think one barrier is that clinicians tend to underestimate the actual utility of the family history. The way that we can get past that hump I think is really better teaching and more pervasive role modeling of the effective use of the family history. If those of us who have some particular background in thinking about family history and using it in health care were to demonstrate to others how it can be helpful, I think that the message would spread more effectively.

Of course, another significant factor which becomes more significant with each year's health care changes is the insufficient time, really in the clinical setting often, to obtain, to organize, and to analyze the family history. It's one thing to say family history can be pertinent, but it takes a lot of time to actually collect the information and to be able to set it down in some way that is available in the future and to be able to really analyze and do something with it.

Now, how do we get past that hurdle? Well, there are some creative approaches out there that people have been working on in recent years that I think are just beginning to come to fruition that will help practitioners who are busy do this using less of their time. But if we do that, in fact, do the patients care about this? Well, there are soon to be published data that come from the CDC -- they're not published yet, so I'm not going to tell you about them, but you can look forward to them soon from Muin and his colleagues -- that show that the American public actually is well aware that family history is important to health. But despite that, relatively few people in the general public have actually ever collected health information from relatives to obtain a family health history, which suggests that there, too, is a barrier, an obstacle which needs to be overcome, and that is that even though people are convinced family history can be pertinent and important for their own health, they haven't actually acted on that, which means there are probably some impediments in terms of this being difficult for families and individuals to do.

So what can we do about that was something that a number of agencies within the Department

have been trying to deal with over the last few years, and those include the Surgeon General's office, HRSA, AHRQ, very importantly the CDC, and various parts of the NIH as well. So we've come together to form what's called now, or will be called officially in a little while, the Surgeon General's American Family Health Initiative. So let me tell you a little bit about this initiative.

The goals of the initiative are, first of all, to increase the American public's awareness of the importance of family history and health, though we again have some data that they're fairly aware of this already, but not so true at the moment is to give the American public tools to be able to gather, understand, evaluate, and use family history to improve their health; to increase the awareness of health professionals about the importance of family history; to give those health professionals tools to be able to gather, evaluate and use family health information, and tools to communicate with their patients about family history; to use this as a way to increase both the genomics literacy and health literacy in general. If we're going to get the public ready to use some of these new genomic tools as they become more available, genetic testing, et cetera, it would be a good idea to have folks become more familiar with some of those concepts by using the old tried and true family history. And preparing both the American public and their health professionals for this coming era of genomics in which we believe that will be a regular part of health care.

So what can we do? The first little product of this initiative to point to is something called My Family Health Portrait. You see this is the banner for it. This is a dummy of somewhat what it will look like. If you look closely you'll see that it says "My Family Health Portrait" at the top. In the middle it says "Welcome to Your Family Health Portrait." This is such a dummy that it hasn't been updated to reflect the official name, My Family Health Portrait.

This is going to be a web-based tool that will be unveiled very shortly -- I'll tell you a bit more about that in a moment -- where individuals and families will be able to download directly to their computer so that this information lives only on their computer, not on some government site, which would be illegal amongst other things, and allow people -- not just allow people, but give people, we believe, an easy, interactive kind of way to gather their family health information. Then once they've gathered it, in fact, give them some guidance about what they might do with that information.

So November the 8th, Monday in a few weeks, there will be a formal announcement of the initiative, and there will be the release of the My Family Health Portrait website. There will be a big even downtown. Several agencies within the Department will be cooperating in that. We're going to have some other media around that date, so we're hoping that you will hear a fair bit about it in your local media at that time, as well as national media.

This is the official logo of the thing. There will be this press conference at the National Press Club on November 8th to announce this.

Then on Thanksgiving Day, this is really the focus and this is part of what will be talked about at this press conference. The idea is to make Thanksgiving Day that day when American families by and large traditionally gather together to eat a lot, to watch the Packers on TV and do other kinds of things, to use that family event to actually talk about family history and to gather family history information, the idea that people would have this web-based tool. They could use it that day, they could gather some of the information before, they could gather it afterwards. But the time when the family is really together, when you have Aunt Gladys around who can actually tell you about what you thought you had heard about Uncle Joe or something like that, to get more accurate information.

That is, of course, the other problem with doing this in the office, is that often you have the person who comes in has pretty imprecise information. All the clinicians in the room are nodding their heads. That's the experience of all of us. In fact, when you have the family gathered around is the best time to get more accurate information. To be able to build that over the course of time, we're hoping to make this into an American annual event, that Thanksgiving would be that day. We've all seen that picture, the traditional Norman Rockwell. "Freedom From Want" is what it used to be called. The way I think of it is now that we've finished the family history, let's eat.

We hope to encourage the American public to think that Thanksgiving is the day, before you sit down to raise your cholesterol levels, that you actually talk about family history and gather this information.

The initiative will continue past this year, past this Thanksgiving. We're very eager to have other interested parties, be they federal agencies, and particularly non-federal agencies, other organizations, et cetera, that we've had some communications with previously to the degree that we're legally allowed to do that, we're very much hoping that this will be something that not just the genetics community, certainly the genetics community but other communities will participate in it and seize an important idea to bring this tool that we really know can make a difference in health care and can be fairly easily accomplished, that we be able to do that in a much better way.

So with that, I'm going to stop. Mr. Chairman, I don't know if there's time for any questions or comments. If folks have them, I'd be happy to take any.

DR. TUCKSON: Oh, we actually do have just a second. This is an important presentation.

Let me just turn to Ed. I think he has a comment first.

DR. McCABE: Well, I just wanted to comment that I teach the medical students. I had three hours with them last week and I told them that this was the cheapest but perhaps the best genetic test that we had today.

The other thing is I was shaking my head because I recalled that as a geneticist, as a board-certified medical geneticist, I was always asking my patients for their family history, and I realized that I was asking them for more than I could provide myself, and sat down with my mother and went over the family history and learned quite a bit about myself that I had not known. Soon thereafter, she developed Alzheimer's disease, so it was very important that we were able to record that information and store it away in the family Bible so that it can be then utilized by generations to come.

So this is an extremely important tool. I think too few of us take the time to really get that information, and I would encourage everyone here today to be sure that you can do for your families what we as geneticists ask our patients to do for us.

DR. TUCKSON: Any other quick questions or comments?

(No response.)

DR. TUCKSON: Alan, thank you so much.

Let me just ask two follow-ups, then, because I think you've got two things that I think we need to

sort of get some more information about. First is that whatever is going to go out on this in terms of genetics and literacy, which is part of this, the whole idea of why is this important in a genomic age to the public and how do you use this information, we sure would like to, I think, see that and benefit from whatever is being sent out, because that may help us through some of our efforts to improve the public literacy around the issues of genetics. So I think it would be a great FYI for us.

Secondly, if there's any part of this tool that's going to be used as part of any of the agency's efforts around information technology, electronic medical records, I think it would be useful for us to also have that as an FYI follow-up, because we're going to obviously wind up having to deal with those issues downstream. So if this is going to be integrated in any way into any of the new health information technology efforts that are coming out of the government, it will be interesting to see.

DR. GUTTMACHER: Well, certainly, we welcome the opportunity to keep the committee aware of this and also to ask input from the committee and through the committee, the various folks that the folks the committee is connected to, because again, this is the first stage of what we hope will be a long-term kind of initiative. So we'd be very happy -- for instance, we are developing not just a computer base but also pamphlets and those kinds of things that we would love organizations interested in distributing those, which is often the biggest challenge, of course, with the printed word, how to distribute them.

We're developing many of these things. For instance, the computer base too, I should tell you, will be available not just in English but also in Spanish before Thanksgiving, so that we'd love the opportunity to interact with the committee as this goes forward. Thank you.

DR. TUCKSON: Well, to bring this to closure, let me offer three quick possibilities that we might be able to do. Unless there's a major controversy, we might try to get an endorsement.

First, that we endorse the importance of family history as a tool in medicine apropos Ed's comments.

Number two, that we report to the Secretary that we are encouraged to see HHS agencies working together to bring this to fruition.

Third, that we would encourage those agencies that are not part of this to get involved.

So we would at least be supportive of this with those three recommendations.

Is there any discussion about those three?

Emily?

DR. WINN-DEEN: I just wanted to ask a question. Are you going to provide some kind of a mailout so that you could take a pamphlet or something and mail it to your elderly relatives and ask them at their leisure, for those of them that aren't computer literate and aren't able to deal with that, to send information back?

DR. GUTTMACHER: There will be a pamphlet which will explain sort of the role of family history, why it's important for specific disorders, and has a template in which you can record information that we made available.

SACGHS Meeting Transcript  
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DR. TUCKSON: So with that, by a show of hands, would you support endorsing the importance of family history as a tool in medicine, that we report to the Secretary that we're encouraged to see HHS agencies working together to get this done, and third, that we would encourage other agencies to get involved and support this initiative?

All those in favor of that transmission, say aye, or raise you hand, same thing.

(Chorus of ayes.)

DR. TUCKSON: Anybody opposed?

(No response.)

DR. TUCKSON: Terrific.

For a follow-up, Alan, I hope we do get those two follow-ups so that we can see what actually does go out.

DR. GUTTMACHER: Very good.

DR. TUCKSON: Thank you.

DR. GUTTMACHER: Thank you, appreciate it.